## Testimony Prepared for Medicaid Section 1115 Demonstration Waiver Application Department of Social and Health Services

By

Cris Salsbury, Chair Washington Intractable Chronic Pain Association (WICPA)

May 21, 2002

My name is Cris Salsbury. Thank you for allowing me to speak on the Medicaid waiver proposals. I represent over 700 chronic pain patients and health providers in Washington state as chair of the Washington Intractable Chronic Pain Association (WICPA). Since approximately 72% of our patients are low-income and/or unable to work (as per our 1997 survey), we are extremely concerned by the current Medicaid waiver proposals.

Historically, people who suffer from chronic pain are probably the most vulnerable population (and one of the most expensive) in this state or country. Once proud, productive citizens, most are now degraded as losses multiply in their lives -- loss of jobs, family and social structure, independence and basic abilities to perform minimal tasks, dignity, and total loss of any quality of life. Instead of working and providing for their families, they now drain state and federal resources by *unwanted* dependence on medical and other government resources. No one chooses this life. It is forced on people through illness, accidents, and a breakdown of body systems. It is incredibly discouraging and degrading to have to ask or depend on others for all medical services, yet there is no alternative for most. Untreated or undertreated pain causes deterioration of almost every system in the body, thus creating additional medical problems. Thousands of patients regularly have to choose between food, heat, or health. Proper medical care can help many overcome pain disabilities, but these proposals may make access to adequate care impossible.

Of greatest concern are: 1) access to appropriate care, 2) potential co-pays and premium provisions, 3) the possibility of enrollment freezes, and 4) limitations or disruption of benefits "per categorical populations".

The Nov. 1, 2001, version of the waiver proposal states that "Washington's demonstration will ensure that its vulnerable populations continue to have access to medically appropriate care they need." At this time so many practitioners have stopped accepting Medicaid, it is almost impossible for chronic pain patients to find general practitioners, let alone pain specialists. Few physicians yet understand the changes in pain management rules and guidelines adopted 1996-2000. They continue to fear "loss of license" when appropriately treating with opioids. I know of no more than 30 Washington state physicians who are willing or know how to treat pain appropriately at this time. Of those 30, only one or two are willing to accept Medicaid. Those one or two are expected to treat thousands of Medicaid-reliant pain patients. Add additional reporting requirements, paperwork or prior authorization requirements to the physician's Medicaid responsibilities, and that number will be down to zero. Until fewer restrictions and higher reimbursements are available to practitioners, it will be impossible for patients to receive adequate pain management.

Potential co-pays and premiums add to patient stress and will be impossible for many chronic pain patients to handle. Many chronic pain patients utilize multiple medications for adequate care, medications that most

tikely would not be on a "preferred drug list". These medications, like Oxycontin and the Duragesic patch, are often the only drugs that work for moderate to severe pain, are incredibly expensive and generic replacements are not yet available. Those that might be available through a "preferred" list (i.e. Vicodin) are mostly short-acting and cannot be taken for moderate to severe pain. The patient would too soon reach toxic levels by taking the number of pills necessary to manage their pain. Co-pays could easily average \$25-\$40 per month and few Medicaid pain patients have that much extra cash. Premiums would be totally impossible. When having to choose between food, housing and health care, the basic essentials will always win. Patients will decide they can put off health care a bit longer, that it is selfish to worry about his- or herself when a child needs food. By delaying, their bodies will further deteriorate, thus creating additional and more expensive health care needs. There is also a possibility that requiring co-pays and/or premiums will encourage even legitimate pain patients into diversion, something they'd never consider otherwise. But if selling a couple of Oxycontin and doing without care for just a few hours would pay for their co-pay where otherwise they would have no medication, some would be tempted.

The possibility of enrollment freezes means, most likely, that Medicaid will not meet one of its basic tenets – to ensure that its vulnerable populations continue to have access to medically appropriate care they need. People who become disabled during one of the freeze periods will not receive any care, thus increasing costs because delays cause further deterioration in the health of pain patients. However, if those patients receive adequate care immediately, chances increase that they can improve enough to eventually return to work. Freezes do not make sense fiscally or humanely.

Enrollment and benefit limits will most likely affect the disabled and elderly. If one studies even briefly the charts prepared for this proposal, it's easy to note that while the number of disabled and blind patients has remained approximately the same the last several years, health care costs for the disabled and elderly have increased far faster than any other population. Costs for care for low-income children and adults, however, have proportionately decreased. If DSHS or MAA is allowed to "prioritize categorical populations that would first be subject to enrollment limits" they will choose to place limits on the most cost-dependent populations. Again, the more vulnerable one is, the more likely they are to have benefits cut or limited. Medicaid already cut access to medications such as Oxycontin and Duragesic saying they were too expensive and limited patients to no more than 60 pills per month. These patients are already receiving limited care and will be the primary target when Medicaid uses its discretion to "prioritize" populations.

While understanding that something has to change to balance the increasing costs of care and decreasing available funds, the waiver proposals are not the answer. Why is it that every time government has to cut costs, it immediately looks to cutting benefits or increasing costs to the individual rather than decreasing

overhead? We're losing our humanity to fiscal concerns and need to at least maintain, if not increase,

present services instead of considering cuts to those who can least afford to deal with them.

It would seem that a reorganization of how care is delivered and managed would be far more effective than

cutting services. I have worked with many government entities and find that the layers of bureaucracy

create tremendous expense for almost all programs/projects. Assigning case managers who could

coordinate patient care would help reduce duplication of services, improve efficiencies and decrease costs.

Reducing the number of department, section and miscellaneous managers would decrease costs. When a

local utility company in Spokane was facing financial shortfalls, management took pay cuts of 10%-25%.

There is no reason, in the name of humane care, government managers could not do the same. And, the

legislature needs to reassess it's priorities so new stadiums do not take precedence over human life.

One last point: This waiver proposal has few specifics and seems to allow Medicaid wide latitude with few

cross checks for safety, humane consideration or fiscal responsibility. This, or any similar proposal, should

require review and adoption by all appropriate agencies and legislators before submission to HHS.

Budgetary considerations should NOT be the primary factor.

Again, thank you for your consideration. Feel free to contact me at 509/328-8534 if you have questions or

comments on our testimony.

Respectfully submitted,

Cris Salsbury, Chair

WICPA

PO Box 10019

Spokane, WA 99209-0019

509/328-8534

Criswicpa a aol.com